



Insulin Dependent Diabetes Trust

Parents' Supplement



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If we have not grown up with diabetes then we do not know how it feels – the difficulties, the conflicts and the worries that children with diabetes may have. Diabetes in the family is a new experience for all of us, we have no previous experience to guide us through it and it is a continual learning curve. We, as parents, can only do our best.

There are two aspects to living with diabetes, first the practical one of its management, injections, blood tests, diet etc. Information about this aspect is readily available and so this Supplement does not cover practical diabetes management. The second aspect is learning to live with this chronic condition and emotional and psychological ramifications for parents and their children. This aspect still appears to be treated with far less importance and yet understanding the

difficulties that may arise and the reasons they happen, could make life so much easier for the whole family.

The central feature of this Supplement is an article by Dr Clare Williams entitled 'Teenagers with Diabetes' and looks at the role of parents in helping their teenagers to become independent. It makes very interesting reading and I suspect not just for parents of children with diabetes.



Dianosis

The role of parents and their involvement in day to day living with diabetes is very different according to the age of their child when

diagnosed. If your child is diagnosed when young, then as a parent, you are taking full responsibility for your child's diabetes everyday and for 24 hours a day. If your child is a teenager when diagnosed then very often the teenager takes immediate responsibility for injections, blood testing, diet etc and the parents role is one of watching over with less direct involvement. This may sound easier but in many ways it isn't, especially if your involvement in the diabetes clinic educational programme has been minimal.

However, whatever the age of your child when diabetes is diagnosed, it is a difficult and often traumatic time and most parents go through similar feelings. Parents care deeply for their children and it would not be natural if they did not go through a period of grief and sadness. Many parents will recognise the following feelings:

Shock – that this can happen to our child

Denial – 'This can't be happening to my child'. 'I'll wake up in the morning and it will have been a bad dream.'

Anger – 'Why my child?' 'Why not someone else's child?'

Sadness and grief – a sense of loss for the healthy child you had and for the expectations you had for your once healthy child.

Guilt – 'Is it something that I have done?' 'Could I have prevented it?' Guilt is not a rational feeling because it is certainly not anyone's fault when a child has diabetes. But Mums especially seem to feel guilt when their child is diagnosed and probably for a long time afterwards.

The need to know – many parents go through the stage of wanting to know why their child has diabetes and where it came from. This seems to be part of the process, a need to blame someone or something, perhaps this helps to ease the burden of 'guilt'.

Responsibility – it seems that the whole future health of your child rests on your shoulders. This is a huge weight to carry around.

Parents of children and teenagers with diabetes are very special sorts of carers. They are suddenly faced with the diagnosis of their child/teenager and at the same time, the loss of their healthy child. They are bombarded with information about insulin, diet, blood tests, blood glucose control, hyper and hypoglycaemia and the future health of their child. It is a difficult time for the whole family and there are many worries, fears and concerns. Knowing that you are not alone with the experiences of living with diabetes in your child/teenager can be of help and comfort but there is one message that needs to be remembered.

Whatever the cause of your child's diabetes and however you may feel, it is not your fault that it has happened and there is nothing you could have done to prevent it.

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Looking Back On Diagnosis

Jenny Hirst

My daughter was diagnosed soon after her fifth birthday 25 years ago, a Friday evening that I shall never forget!

During her stay in hospital we were given masses of information about diabetes by innumerable different people – hypers, hypos, diet, exercise and shown how to inject. No one seemed to understand that I could not take all this in, the shock of diagnosis and accepting this, was all my mind could deal with. When we left hospital, along with all the other feelings of shock and grief, I felt alone, frightened and very ignorant about diabetes.

We started life with diabetes having been given some very clear messages by the healthcare professionals:

- diabetes was with us forever and my little girl would have insulin injections for the rest of her life.

- we needed to keep ‘good control’ of her diabetes to avoid the complications in later life and this was a simple matter of injecting the right amount of insulin to balance with the food. [I soon learnt that this was rubbish, there is nothing simple about achieving ‘good’ control!]
- she could live a perfectly normal life with diabetes.

I think that these last two statements were confusing, unrealistic and very simplistic. No doubt they were said with the best intentions to cheer me up. They had a long lasting and damaging effect.

Good control is easy– a myth!

I tried to achieve the good control that was expected but it didn’t happen. It took me about three years to realise that perhaps it wasn’t my fault and that diabetes is not simple. Perhaps it was that the expectations of the professionals were too high or perhaps they just did not realise that achieving ‘good control’ can be really difficult, especially in growing children and young people. This was my first realisation that people who live with diabetes have knowledge and experience that is different from that of the healthcare professionals and that I could no longer simply rely on the information I was given. I had to make decisions and judgements for myself and have confidence in them.

Normal life – a misunderstanding!

I also waited for the normal life I had been promised to appear. It didn’t seem to arrive and I felt that this was my fault – I must be doing something wrong and I felt as if it was my inability to manage that was preventing us from having this ‘normal life’ the doctors and nurses had promised. I felt a failure. That one statement led me to expect that life would go back to normal – normal to me was how it had been before diabetes. Had this not been said to me, my expectations would have been different and I would not have felt such a failure nor so much guilt for not achieving this ‘normal’ life we had been promised.

And now?

Life has been normal now for many years – diabetes just became part of our lives, a part that does affect the whole family and a part that

cannot be ignored. We all have feelings about diabetes, especially the child/teenager with it. We found that it was important to talk about these feelings within the family. Joining a parents support group provided another outlet to express some of the very real feelings and in a non-judgemental situation with people who actually understand. This way the feelings seem normal, and are normal, when living with diabetes. Once I realised that our experiences were similar to those of many other people, that I was not the only one who could not always achieve the standards set by the clinic and that I was not a failure, life became much better for us all. Looking back now over the 25 years, I know that some of my feelings that I had at diagnosis are still there – the guilt, the sadness and the responsibility. But I also now know that I have always done my personal best. This ‘best’ may not seem as good as someone else’s best but it was my best.



Teenagers Living With Diabetes

Dr Clare Williams, Institute of Education, University of London

Through working as a nurse and a health visitor for 20 years I had become very interested in the different ways in which people incorporate conditions and treatments into their lives. When the chance came to study for a PhD, I decided to look at how teenagers with diabetes live with their condition. Being the mother of a teenage girl, I was also interested in the role that parents play in helping their teenagers to become independent. Instead of sending out questionnaires to lots of people, the type of research I chose to do – qualitative research – aimed to explore the experiences of fewer people in much more depth, to find out their perspectives.

Who did I interview?

I interviewed 20 teenagers between the ages of 15-18 years, ten boys and ten girls. I also interviewed whichever parent the teenager said helped them the most with their diabetes management – in all

cases this was the mother. I wanted to interview people from as many different settings as possible, so I contacted various hospitals and GPs in my area. I received a good response when I placed letters in 'Young Balance' and 'Balance' asking for anyone interested to contact me. I also talked about my research to whoever would listen and made some contacts that way.

What did I find?

Did mothers think that teenage girls and boys had different needs? Mothers of girls were much more likely to talk about their daughters being in control and responsible than the mothers of sons, both generally and in relation to the way they managed diabetes. Daughters and sons were seen by mothers as having different needs, although this wasn't because sons were seen as sicker than daughters. In fact, the mothers of boys were much more likely to describe their sons as very fit than the mothers of daughters. Instead, boys were seen as less able to care for themselves than girls of the same age and consequently, as more in need of the help of their mothers. I'm going to use some quotes from the people I interviewed to illustrate the various points, but I have changed the names so they can't be identified. For example Martin's mother told me:

“Girls always seem more organised I find, and you know, she'll take the little blood testing kit or whatever for going away, everything is packed and organised whereas Martin will, as we're going down the road, say “Oh, did you get my insulin?” (son aged 15 years and daughter aged 12 years, both with diabetes).

Did teenage boys and girls manage diabetes in a different way?

Yes, there did appear to be a marked difference in how the majority of teenage boys and girls I interviewed lived with diabetes.

Boys' management of diabetes

The boys I interviewed were much more likely than the girls to describe diabetes as only having minimal effect on their lives. They were also much more likely to try and keep diabetes and its treatment hidden in public settings, as far as they could. This meant, for example, that they

were much less likely than the girls interviewed to give themselves injections at school. Martin's mother told me:

“He won't do them (blood sugars) at school now, he absolutely refuses, he won't even do an injection at school. He is on three injection a day and the hospital would like him to go on to four but he won't do it in front of his friends, and he doesn't like the fact that he is diabetic in that respect, he wants to be normal.”

Mothers often helped their sons to 'hide' diabetes in public, and this was one of the reasons that mothers felt boys needed more help than girls. Julian's mother told me:

“His diabetes is managed purely from here (home) – once he goes out of the door as long as he has got some glucose tablets and his lunch in his bag, he's no different to anyone else, which is good really”.

It seemed that the teenage boys interviewed were worried that any signs of 'illness' could be seen as a weakness by others. Consequently, boys tended not to talk about diabetes with friends and often chose not to tell teachers about it, which meant that their mothers sometimes had to do this for them. For example, mothers told me that if they were worried about their son they might ring up the school, but this wouldn't be discussed with their sons. A lot of the help that mothers gave their sons tended to be 'invisible', in that the boys didn't seem to realise that things were being done on their behalf. In fact, many mothers felt guilty for giving the help they did, as they often felt under pressure from health professionals to encourage their sons to be independent. This is similar to research findings on adults, where women tend to be the family members who take care of health in a variety of subtle ways.

The majority of boys I interviewed had good control of their diabetes. They tended to manage diabetes in a fairly 'rigid' way, which meant that they felt in control of it and it was 'no big deal'. However, there was a small minority of young men with serious problems that I only came

into contact with through my letter in Balance. I was contacted by their mothers, but the young men themselves refused to be interviewed. The lives of these mothers were severely affected because of their knowledge about their sons' non-adherence to treatment. Harry's mother told me:

“He tells people that he’ll be dead soon anyway so it doesn’t matter what he does, and that seems to be his whole attitude really....so I’ve given up now, I might as well not say anything.... he just doesn’t want to do it, he doesn’t want to know....I feel like I’m watching him kill himself, and there’s nothing I can do about it, absolutely nothing”.

The results of my study indicate that teenage boys are more likely than teenage girls to move between two extremes, with the majority managing very well and a small minority managing very poorly. As mothers are likely to be involved in helping boys manage, they are usually the first person to detect problems arising. However, some mothers reported that when they alerted health professionals, they were made to feel as if they were ‘fussing’ unnecessarily.

Girls’ management of diabetes

It seemed more acceptable for girls to admit that they had diabetes, and girls were much more likely to tell teachers and their friends about it. In many ways the girls I interviewed appeared – superficially at least- to manage diabetes well. For example, they were much more likely to follow the four injections a day regime often recommended by health professionals, which meant performing insulin injections at school. However, there were other factors which affected their overall control which I think may tie in with the BDA Cohort Study findings, which identified young women with diabetes as at a greater risk of premature death than young men.

Firstly, I found that teenage girls had often felt under pressure from health professionals to take responsibility for their diabetes management and mothers had little control over the situation. Susan’s mother said:

“I have never once given her an injection from the age of eight – she has always refused any help, and I used to think that maybe sometimes this was far, far too much for her. It was (from the medical profession), “it’s your diabetes Susan, you’re in control, you’ve got to handle this, and you’ll be responsible”, and I mean, she just sort of took this on board and that was the end of it”.

Following publication of my letter in Balance I was contacted by a number of young women in their 20s who wanted to talk to me about their experiences as teenagers with diabetes. One of these, Louise, reflected back on when she was first diagnosed as having diabetes at the age of 11 years:

“My mum told me that the hospital stressed very much that my parents, they needed to let me have control –I was old enough to be able to do this myself....so as soon as I came out of hospital it was all down to me.... I showed I could cope in a way on the outside, but on the inside – the emotional side I couldn’t cope with it all, I didn’t really start coping until I left home”.

One of the consequences of this was that the mothers of teenage girls seldom had much knowledge about how their daughters managed diabetes, in contrast to the mothers of boys, who tended to be more involved in the day to day management themselves. The level of control girls chose to achieve was very much up to them, whereas most of the boys were advised and supported by their mothers.

Of the ten girls interviewed, four had intentionally had often lengthy, and potentially harmful periods of non-adherence to treatment, of which their mothers, and others, were usually unaware. This could take the form of injecting themselves with less insulin than they needed, or even skipping injections completely. It was hard for the girls to explain why they did this, because they often made themselves feel ill. Whatever the cause, one of the resulting effects was that many of the girls expressed feelings of guilt and shame which were not expressed by boys. Reena told me:

“I do feel guilty quite a lot, because I’m thinking, “I’ve ruined everything”. Like, the doctor said I would have been taller but he said it was because I didn’t control it that well I haven’t grown that much”.

Two specific aspects of diabetes management which also led to girls expressing feelings of guilt were diet and exercise, and these were also the two main reasons that girls saw themselves as ‘unhealthy’. Teenage girls are generally more concerned about their body shape and weight than boys, and it seems that the emphasis on food and weight in the management of diabetes can bring additional problems for girls. Jemma told me:

“I’m on a diet now because I’ve been eating too much and I want to lose weight. I’m conscious of how much I weigh, and even though I eat, I know I shouldn’t be eating so I feel terribly guilty and go out and eat some more because I feel guilty, and it’s a vicious circle, so I’m not healthy at all”.

Similarly, the value of exercise in controlling diabetes could also disadvantage teenage girls, who often participate in little exercise or sport. This in contrast to most of the boys, who usually played a lot of sport and described themselves as very fit.

I have tried here to present some of the key findings from my research, although it has been very difficult to summarise 90,000 words succinctly! I would be really interested in any thoughts you might have about the issues raised. I have also written articles for health professionals, although I know that many read the IDDT newsletter. I can’t finish without saying a very big thank you to everyone who went out of their way to help me with my research.

Parents Views

There has been progress in the way diabetes is managed – blood testing, HbA1c measurements, and practicalities such as injection pens. But it is questionable whether progress has been made in learning how to cope with diagnosis and with hypoglycaemia, in understanding how to live with diabetes in the family, the emotional difficulties, the conflicts that arise and the stress that is placed upon parents and relationships within the family. Research [ref 1] carried out in 1998 in the US found that behaviour problems in children with IDDM are not related to the medical diagnosis of diabetes, but to their mother’s depression and distress in both parents at diagnosis. The children did not appear to react to the diagnosis of a serious medical condition but they did react to their parents’ reactions.

Indeed, it may be that present day treatment of diabetes with tight control [intensive therapy] resulting in increases in the number of hypoglycaemia attacks, actually increases the psychological effects and stress on parents. However, research [ref 3] comparing children on intensive therapy and conventional therapy showed that there was no difference in the depression of parents, it was present in both groups and it was not associated with HbA1c levels, duration of diabetes, patient age, parent age, family size or family income.

An earlier study carried out in 1996 into the psychosocial ramifications of childhood diabetes shows that little has improved over the years. Researchers at Leicester General Infirmary [ref 2] carried out semi-structured interviews with the parents to look at the effects of childhood diabetes on the family. They concluded that the ramifications of childhood diabetes were marked even in the so-called ‘well-adjusted family’. All parents reported sustained additional stress, more intense in mothers, especially single mothers. Hypoglycaemia was a constant major anxiety and 6 families had not been warned about severe hypos. Family cohesiveness was strong and sibling rivalry and jealousy did not feature. Diabetes was at the centre of family functioning.

The parents' views were:

- Their education about diabetes varied, although all said it was good initially, 70% felt that it had been withdrawn too early.
- More practical dietary advice would have been appreciated.
- All felt they would have benefited from more counselling and help with learning to cope.

From these studies alone it is apparent that while there have been developments in the treatment of diabetes and there may be a greater awareness of the difficulties that parents face, many things facing families with diabetes sadly have not improved.

Ref 1 Arthritis Care and Research 1998; 11: 166-176

Ref 2 Diabetic Medicine 1996: EPCS abstracts and posters

Ref 3 Diabetes Care, Vol 22, No8, Aug 1999

A Plea To Health Professionals, From Parents!

Parents of teenagers with diabetes are often in a 'Catch 22' situation in relation to healthcare professionals. They are told that they should allow their teenagers to become more independent – indeed, they are often blamed by healthcare professionals for overprotecting their children, but if independence leads to any problems in management, then mothers can be blamed for this too! Mothers often have to tread a very fine line, one that is not always clear or understood by those issuing the advice or the blame! They can end up pretending to the healthcare professionals that they are not involved in their child's care for which they feel guilty.

It is not unusual for the mother of a teenager not to be involved by the healthcare professional or even to be told that any problems with the

diabetes belong to their teenager and not them. But it is very hard for the mother to do nothing, especially if the difficulties are affecting the whole family. All too often mothers are placed in an almost impossible situation and one that needs the support and understanding of the healthcare professionals involved.

Growing Up With Diabetes

Growing up is not easy and growing up with diabetes or any chronic condition makes life that much more difficult for your child. This is something that we, as parents, can recognise and try to understand, but unless we have actually had the experience ourselves we don't know how it really feels. This is perhaps something that our teenagers with diabetes will remind us of on many occasions!

Here are just some of the experiences that our children may have as they grow up:

- Feeling different from other children. Being treated differently from other children at home, at school and socially.
- Not feeling as good as their friends, having a low self-esteem. Being aggressively determined to be as good, if not better, than everyone else.
- Being frightened of looking foolish if they have a hypo.
- Feeling pressurised by messages of being 'normal' when they don't feel always feel 'normal'.
- Being excluded from school activities or parties because they have diabetes.

It is difficult to grow up with diabetes from a young age and perhaps never know what it is like to not have diabetes and be treated normally. But it is equally difficult to be diagnosed in the teenage years – perhaps more difficult. At one of the most difficult stages of growing up, your teenager is suddenly being faced with diabetes and all the changes

that this means in both lifestyle and self-image.

A quote from a 25 year old with diabetes for 20 years. “Nobody wants diabetes but if I had to have it, I’m glad I got it when I was young and can’t remember life without it. Being diabetic is just part of me and not something that suddenly hit me. I didn’t have to get used to any great changes in my life or adjustments in my lifestyle or self image.”

‘Letting Go’ - Never Easy For Parents

One of the aims of parents is to see their children grow up to live full and independent lives and this means letting them go. Parents whose children have diabetes are no exception but letting go is harder because there are not only all the ‘normal’ worries, but there are the additional worries associated with diabetes. The process of letting go starts at an early age, when children go to nursery or school, but the real difficulties and conflicts start in the teenage years.

Teenagers are teenagers with or without diabetes, they do not want to be different from their friends. They are going to go into pubs, drink, even smoke and come into contact with drugs – just like any other teenager today. Their friends stay the night away from home, go to all night parties, pop concerts and back pack abroad in strange countries. Teenagers with diabetes will want to do all this - and so they should, but from a parent’s perspective, this really means letting go not only of their ‘child’ but also of their child’s diabetes. It also means taking risks, having faith and trust in your teenager and keeping your fingers crossed while biting your finger nails!

Negotiation

Letting go and giving teenagers the freedom they want and need is all about negotiation, whether they have diabetes or not. The parent says “if you are going to be late, phone and let me know, then I won’t

worry”. This is not a refusal to allow them to be late but in return they should phone. It the sort of negotiation that goes on all the time. But these negotiations are often more complex in teenagers with diabetes, who are all too often ready to accuse the parent of stopping them from doing things because they have diabetes. Perhaps they are right, it is our fears for them, as parents, that make us want to stop them doing the riskier things. But we also have to recognise that they learn by their mistakes and we have to hope that the mistakes are not too serious.

From the mother of a teenager with diabetes: “Her friends had just come across alcohol and she wanted to drink like them. She did not heed my warnings that alcohol lowers the blood sugars and had a couple of awful night hypos, with me looking after her through the night. I said I wasn’t doing it again when it was because she had drunk too much and she felt so awful that she never did do it again.”

Lack of negotiation can only result in conflict - you can insist that they do the right thing, but you cannot make them. Conflict can lead to resentment and a breaking down of family relationships probably at a time when your teenager needs you the most, even though they would not admit it. It may be that you are not needed in the way you were – to manage their diabetes and their lives for them, but to just be there, to boost their confidence by showing that you trust them [even if you don’t always!] and to pick up the pieces when necessary.

After the negotiations, what next?

Letting go means having trust, faith and hope! Teenagers with diabetes will want to do all the things their friends do and as a parent while they are doing them, you have to hope and trust that in the long run common sense and self-preservation will prevail. Hope that in the short term if he/she does have a hypo (usually the biggest worry) it won’t be that bad that he/she can’t handle it. Faith is very important and sometimes very difficult when we see our teenager at home breaking all the rules, being stropky and from time to time being fairly

objectionable! But having faith is very important to give your teenager the confidence they often badly need.

We have to let go of our children. If they make mistakes in the process, then we have to hope that they are not too serious or damaging, but equally we have to be there for them when they need us. That is a parent's role, made more difficult by diabetes but even more necessary.

We are very aware that this Supplement contains no articles for parents written by children or teenagers with diabetes. This is not an error or an accidental omission but perhaps recognises reality! Should we really expect our children, and especially our teenagers, to take time out of their busy lives to sit down and write about diabetes for parents? We would be happy to receive such articles or their comments on the Supplement but recognise that to subject any of them to a request to write for us is perhaps not the best idea from their point of view – just one more nuisance related to diabetes!

The Parents' Supplement was published in August 2000 by IDDT and we are happy to supply copies of this Supplement free of charge.

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Visit our web site www.iddtinternational.org

Also worth paying a visit to www.teenagediabetes.co.uk

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From Your Editor – Jenny Hirst

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